

As soon as the cleft was discovered, the Cleft team at Addenbrookes were contacted and the lovely Susan Burton came to see me on the ward the same day. She brought with her a new baby "welcome pack" from the CLAPA Cambridge branch. This was our first dealing with CLAPA and in particular the Cambridge branch. I had no idea at that point how much of a help CLAPA would be to our family and how 3 years later, I am now trying to help others as a member of the Cambridge CLAPA committee.

The welcome pack contained a squeeze bottle, a little teddy (which Molly treasures), a card and some information leaflets. The leaflets and details of CLAPA's website provided useful information for us, as up until this point we had very little knowledge of clefts and the impact it would have. Although the squeeze bottle was provided, Molly unfortunately was never able to take milk from a bottle. Her cleft was just too wide and her prematurity meant she was just wasn't strong enough.

Our first real meeting with the CLAPA people was at the Christmas Party the year Molly was born. We saw the details on the main CLAPA website and thought it would be a nice thing for our older daughter Jaimee to attend (Molly being much too young at that point). We was very aware that although it was Molly who had the cleft, the attention we had to give Molly and the numerous hospital appointments meant that Jaimee could unintentionally be given a back seat. We saw the party as a way of her getting something positive out of the experience. It proved a great hit and we have only missed one party since then! Jaimee and her Dad have also been lucky enough to attend a couple of the Silverstone race days that CLAPA organised. The people at head office were more than happy for Jaimee to attend as a sibling of a cleft baby.

So three years after Molly's birth where are we? Well Molly had 4 operations before her second birthday. Two on her cleft. She had the NG tube removed at 9 months and had her first palate operation at 11 months. As I said the cleft was very wide and whilst her surgeon the lovely Tariq Ahmad was cautiously optimistic, we were warned that she might develop a fistula. Within a week it became apparent that this was the case. Molly monitored over the next year and while the fistula did close a little it remained open and the consensus was that it was going to have an effect on speech development so it was decided to close it. At 22 months, Molly was back at Addenbrookes and had the fistula repaired and her palate extended at the same time. This operation was a great success. As for the PRS, Molly as predicted has grown into her chin, her palate has been repaired and after much encouraging her to poke her tongue out her tongue has come forward. We are lucky that she hasn't had any of the breathing problems that can be associated with PRS babies. Molly continues to have follow ups with cleft team. Her hearing is monitored regularly. She has ongoing speech therapy for problems with her speech but is able to make herself understood with a combination of speech and Makaton signing. She is very low in weight for her age and is reluctant to eat but she follows her own little line and we are happy with that.

We have continued to attend the Cambridge branch parties and started to wonder if there was anything we could do to say Thank you. Jaimee organised a non-uniform day at her school to raise money for CLAPA, it was at this point that I got involved in the committee. Her headmaster suggested that someone from CLAPA could go in and talk to the children about CLAPA. Somewhere along the lines myself and Mary Newbold ended up taking the assembly – one of the most nerve wracking things we've done, 300 primary school children are scary! Since joining the committee I've been able to help out at the recent AGM and been involved in some of the coffee mornings at Clinic 7. The feedback we've had for the mornings have been great, it's really good to be able to help the children and parents in a little way.

I am more than happy for anyone to contact me if you think I can help in anyway. I've got 9 months experience of NG-tube feeding; numerous operations; speech problems and low weight. But most of all I'm just a Mum to a very happy, cheeky little girl who had a bit of a tough start in life but lets nothing stop her and as with all cleft children is incredibly strong and never ceases to amaze us with how she coped when she was tiny and what she has achieved since.